AMENDED IN ASSEMBLY MAY 5, 2009 AMENDED IN ASSEMBLY APRIL 22, 2009

CALIFORNIA LEGISLATURE—2009–10 REGULAR SESSION

ASSEMBLY BILL

No. 1307

Introduced by Assembly Member Buchanan (Coauthors: Assembly Members Portantino and Torres)

February 27, 2009

An act to amend Section 125001 of the Health and Safety Code, relating to newborn screening, and making an appropriation thereof.

LEGISLATIVE COUNSEL'S DIGEST

AB 1307, as amended, Buchanan. Newborn genetic screening. Existing law requires that the State Department of Public Health establish a statewide program for the screening of newborns for specified genetic disorders, including tandem mass spectrometry screening for fatty acid oxidation, amino acid, and organic acid disorders and congenital adrenal hyperplasia. Existing law creates the Genetic Disease Testing Fund in the State Treasury, which is used to fund the newborn

screening program.

This bill would require, prior to January 1, 2011, the statewide screening program to also include all conditions recommended by the American College of Medical Genetics (ACMG) as of January 1, 2010. This bill would also require the department to consider future inclusion in the statewide screening program of conditions recommended by the ACMG American College of Medical Genetics (ACMG) or other specified entities. The department would be required to adopt the recommendations, as specified, within one year of their publication unless the department determines that screening for the recommended

AB 1307 -2-

conditions are is not necessary for advancing newborn health and notifies appropriate committees of the Legislature of that determination. Because this bill would expand the purposes of the screening program it constitutes an appropriation.

Vote: majority. Appropriation: yes. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

SECTION 1. Section 125001 of the Health and Safety Code is amended to read:

125001. (a) The department shall establish a program for the development, provision, and evaluation of genetic disease testing, and may provide laboratory testing facilities or make grants to, contract with, or make payments to, any laboratory that it deems qualified and cost-effective to conduct testing or with any metabolic specialty clinic to provide necessary treatment with qualified specialists. The program shall provide genetic screening and followup services for persons who have the screening.

- (b) (1) The department shall, prior to January 1, 2011, expand statewide screening of newborns to include tandem mass spectrometry screening for fatty acid oxidation, amino acid, and organic acid disorders, and congenital adrenal hyperplasia, as well as all conditions recommended by the American College of Medical Genetics (ACMG) as of January 1, 2010. The
- (2) The department shall also consider including, in the statewide screening program, conditions included in the most recent recommendations of the American College of Medical Genetics (ACMG), as defined by inclusion on the core panel or as secondary targets, or for conditions recommended by another advisory body, appointed by the federal Secretary of Health and Human Services, to make recommendations for newborn screening programs. The department shall implement screening for the recommended conditions within one year of the publication of the recommendations unless the department determines that screening for a specific condition is not necessary for the advancement of newborn health and notifies the appropriate committees of the Legislature of the determination.
- (c) The department shall provide information with respect to these disorders disorders included in the statewide screening

-3- AB 1307

program and available testing resources to all women receiving prenatal care and to all women admitted to a hospital for delivery. If the department is unable to provide this statewide screening by August 1, 2005, the department shall temporarily obtain these testing services through a competitive bid process from one or more public or private laboratories that meet the department's requirements for testing, quality assurance, and reporting. If the department determines that contracting for these services is more cost-effective, and meets the other requirements of this chapter, than purchasing the tandem mass spectrometry equipment themselves, the department shall contract with one or more public or private laboratories.

- (2) Commencing January 1, 2010, the department shall consider additional conditions for screening, as recommended by the ACMG or other governing body appointed to convene, discuss, and establish recommendations for newborn screening programs and approved by the United States Secretary of Health and Human Services. The department shall adopt the recommended conditions for screening, within one year of receipt of the recommendations, unless the department determines that the screening for the recommended condition is not necessary for advancing newborn health, and notifies the appropriate committees of jurisdiction in the Legislature of this determination.
 - (e)

(d) The department shall report to the Legislature regarding the progress of the program on or before July 1, 2006. The report shall include the costs for screening, followup, and treatment as compared to costs and morbidity averted for each condition tested for in the program.